Dying at home: community nurses' views on the impact of informal carers on cancer patients' place of death

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Giving patients with cancer a choice in where they want to die including the choice to die at home if they so wish, underpin the recent UK government policies and is embedded in the End of Life Care Programme. However, this presents increasing challenges for the informal carers particularly with an increasingly aging population. Despite the policy initiatives, there remain a persistent number of patients with cancer who had chosen to die at home being admitted to hospital in the last days and hours of life. A qualitative study using two focus group interviews with community nurses (district nurses and community specialist palliative care nurses) was undertaken across two primary care trusts in the north-west of England. Data were analysed using a thematic analysis approach. The results indicated that informal carer burden was a key reason for prompting hospital admission. Recommendations for the development of a carer assessment tool with appropriate supportive interventions are made.

Keywords: place of death, carers, carer assessment tool.

INTRODUCTION

Within the UK, there is a growing emphasis on increasing the choices for service users particularly with a move from institutional care for patients with chronic and life-limiting illnesses (Payne *et al.* 1999; Arksey & Glendinning 2007; Munday *et al.* 2007). This has been supported by numerous policy documents and acts that have aimed to reshape community care and service provision (Arksey & Glendinning 2007). The redesign of service provision and the emergence of advanced services such as hospital at home, rapid response teams and disease specific teams have developed with the overarching aim of keeping people at home and avoiding hospital admissions.

For patients with cancer, the NHS Cancer Plan (Department of Health 2000), the National Institute for Clinical Excellence Guidelines (NICE 2004), the End of Life Programme, NHS End of Life Care (EOLC) Programme (http://www.endoflifecare.nhs.uk/eolc) introduced in 2003, the Department of Health Cancer Reform Strategy (Department of Health 2007) and the recent Department of Health End of Life Care Strategy (Department of Health 2008) have all helped to develop and expand the provision of palliative care services in the UK. Implicit within these policies and development is that the patient's preferences regarding the location of care are followed (wherever possible) (National Institute for Clinical Excellence 2004).

However, despite these policy initiatives, approximately 56% of UK cancer deaths occur in hospital, despite 90% of terminally ill patients spending most of their last

year of life at home. Analysis of cancer deaths in south-east England reported that between 1985 and 1994, there had been a trend away from deaths in hospital. By 2002, however, this had increased again and home deaths had declined (Davies *et al.* 2006).

Despite the increased community service provision, the input of informal carers to support terminally ill patients has to be recognised. Informal carers were defined in the 2001 UK Census as people who provide unpaid care for family members, neighbours or others who are sick, disabled or elderly (http://www.statistics.gov.uk/census2001). Generally the majority of informal carers are close family members (Neal 1993). It is important to consider the profile of the informal carers; there is an increasingly aging population, a demise of the nuclear family and reducing family sizes, all of which impact negatively on the pool of available informal carers (Dahlberg *et al.* 2007).

Although the role of the informal carer has been recognised with legislation such as the Carers (Recognition and Services) Act (Department of Health 1995), these have generally focused on chronic conditions and disabilities (Dahlberg *et al.* 2007).

For patients with cancer, the increasing range of treatment options, many with debilitating side effects, are resulting in longer disease trajectories. Thus, ensuring a longer period of informal care coupled with the anticipatory loss that the bereavement will bring (Payne *et al.* 1999; Harding & Higginson 2003). The situation can be additionally complex with the period of physical deterioration towards the end of life often being rapid, giving the informal carers little time to adjust to the increasing demands of the role, along with the imminent death (Zapart *et al.* 2007).

Informal carers have been subject to a wide range of studies but the range of carers' needs is vast and encompasses physical, psychological, emotional and financial needs. Studies have identified the impact of being a carer and links to physical and mental health, including depression is reported (Herbert *et al.* 2007). Initiatives to help informal carers have been described in the literature and encompass a wide range of options including service provision and interventions to provide support, education and building coping skills. However, there is limited evidence of their effectiveness, nor are they widely available (Harding & Higginson 2003). Furthermore, although there are specifically designed programmes for informal carers of patients with cancer, few interventions are targeted for those carers of patients at the end of life (Herbert *et al.* 2007).

Several studies have explored factors that impact upon the sustainability of keeping terminally ill patients at home. These report a variety of influencing factors with issues surrounding the informal carers being highlighted. This included the patient living alone (Tiernan *et al.* 2002; Aoun *et al.* 2007) as well as the ability of the carer to cope (Thorpe 1993; Hinton 1994; Karlsen & Addington-Hall 1998; Payne *et al.* 1999; Tang & McCorkle 2003; Davies *et al.* 2006; Foreman *et al.* 2006; McKenzie *et al.* 2007; Zapart *et al.* 2007). In a systematic review of 58 published studies, Gomes and Higginson (2006) identified 17 issues that had an effect on the place of death. These included factors related to illness including the trajectory of the disease, patients' preferences, the level of home care and social support including the presence of informal carers and consideration of the families' wishes for a home death. Having multiple family members to provide the informal care and sharing of responsibilities was identified as important. They concluded that the network of factors that influence where patients with cancer die is complicated and stressed the need for continuing evaluation of policy initiatives.

Although previous studies suggest various influential factors that cause a hospital admission of the dying patient, generally these studies were undertaken before the roll out of the UK End of Life Care Programme and therefore the precipitating factors may now have changed. Despite patients with cancer and their families wanting a home death, there appears to be a substantial number of admissions to hospital in the last few days and hours of life. This was indicated in the locality of the study where an internal audit identified an increasing number of patients with cancer dying in hospital despite having expressed a desire to die at home. This was the impetus for this study (Drijfhout & Groves 2007). Clearly, an understanding of the reasons behind these admissions would be useful to enable strategies to be employed.

METHODS

The aim of the study was to explore district nurses and community specialist palliative care nurses' perceptions and experiences of the factors that influenced hospital admission of patients with cancer in the final stages of life. Therefore, a qualitative method was employed for the study as it is designed to enable exploration of participants' experiences, feelings and beliefs (Holloway & Wheeler 1996; Robbins 1998; Polit & Beck 2006).

SAMPLE

The research took place across two primary care trusts (PCTs) in the north-west of England within one regional

health authority. A purposive sampling approach was adopted to focus upon the conscious selection of certain subjects (Polit & Beck 2006). Two groups of nurses were invited to participate in the study, community specialist palliative care nurses and district nurses. Of the 11 community specialist palliative care nurses in the PCTs, eight volunteered to take part. Approximately 17 district nurses and representatives from the out-of-hours services and older persons' team attend a monthly district-wide palliative care interest group; 11 of these nurses agreed to participate. All participants had been in post for a minimum of 6 months to ensure they had experience of the local service provision.

DATA COLLECTION AND ANALYSIS

Data collection utilised audiotaped focus groups to promote group discussion and debate (Krueger 1994; Kitzinger 1996; Vaughn *et al.* 1996; Bloor *et al.* 2001; Hudson 2003). Two focus group interviews lasting for approximately 1 h were held, comprising eight community specialist palliative care nurses and 11 district nurses. To ensure the nurses were comfortable expressing their professional opinions within the study, it was deemed appropriate to hold separate focus groups for the specialist palliative care nurses and district nurses. The interviews were conducted by the researchers (B.J. and M.O'B.) who acted in the role of moderator for the focus groups.

A semi-structured interview schedule to guide the discussion was adopted for the study. Questions were focused around whether patients died where they had chosen to; factors that may have influenced a change in plan and existing issues that could affect choice. Questions were open-ended and participants were prompted to expand on points and to give clinical examples from their practice where possible. To ensure clarification of the main points and enhance the trustworthiness of the findings, a summary of the key issues raised in each focus group were identified at the end of the interview by the moderator as recommended for the running of focus groups (Jones 2003; Goodman & Evans 2006). This allowed additional comments to be made by the respondents and can lead to the formation of tentative themes being developed.

A thematic analysis approach was adopted using the four stages of organisation, familiarisation, reduction and analysis (Miles & Huberman 1994; Polit & Beck 2006). Each focus group interview was analysed independently by the two researchers to enhance the credibility of the findings. The reduction phase included the coding of the data (May 1998), where categories under each question were identified and subsequently coded. The analysis stage comprised the defining of theme descriptors until all data were fully represented (Miles & Huberman 1994; May 1998). The final themes were discussed by both researchers and a consensus reached.

ETHICS

Ethical approval to undertake the research was obtained from the NHS local Research Ethics Committee, and standard procedures for recruitment and obtaining informed consent were followed. The PCTs' research governance procedures were adhered to throughout the study. Additionally, respondents were informed before the focus group interview that any inadvertent references to patients' names or potential identifying data would be removed at the transcription stage.

RESULTS

Two main themes emerged from the study, service provision and informal carer burden. We focus here on issues relating to carer burden. Both specialist community palliative care nurses and district nurses highlighted the ability of the informal carers to cope as one of the major factors affecting adherence to a patient's choice of place of death. Informal carers are such an important part of end of life care in the community that situations which limit their capacity to cope frequently result in alterations to patients' place of care at this time. A number of contributory factors were identified, including: unrealistic expectations of community services among patients, carers and hospital staff often resulting from a lack of understanding of the role of community staff; the duration of illness and patients' perceptions of their carer's abilities. The delay in provision of community services was also identified in regard to patients being discharged from hospital, and when additional services are required as a patient's condition deteriorates. The themes emerging from the data are illustrated with quotations from the two focus groups; these are representative of the consensus of opinion that was generated in the group discussion and are the topics which produced most deliberation. Respondents are identified as DN for district nurses and CNS for community specialist palliative care nurses.

Unrealistic expectations

It was acknowledged that demand on limited services inevitably results in delays in establishing individual care packages. However, both groups of nurses also identified that there are often unrealistic expectations among

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patients and carers regarding the extent of community service provision. For both groups, this was a major point of discussion. It was felt that some carers made assumptions that involvement of the community nursing team would mean that the time they have to commit to caring could be reduced. This was particularly so for those carers whose working lives have been adversely affected by their caring role.

> I went to see a new patient last week, where the daughter firmly believed that I was virtually going to move in with her mum, so she could go back to work and there would be 24 h, 7 day a week care for her mum from the moment of diagnosis. (CNS)

These unrealistic expectations of the level of care that can be provided within the community are often exacerbated by hospital staff when arranging discharge following diagnosis or treatment.

> I think it is what they are promised in hospital as well though, isn't it, we had one that was promised 24 h care and within 3 days it was just family breakdown. (DN)

There was a feeling that hospital staff do not fully understand the role of district nurses, which may lead to them offering service provision that was simply not possible. This invariably impacts on community staff.

> Whether the staff in the hospital generally aren't aware of what is available out in the district, because sometimes we just can't deliver what they [patients and carers] have been promised and it is very frustrating. (DN)

Similarly, patients and carers are not always familiar with the service provided by district nurses and community specialist palliative care nurses.

> I don't think people understand the role of the district nurse very well in palliative care, because I've come across a few times where they expect the Macmillan nurses to be there, 'where are the Macmillan nurses, why aren't they here?' and we have to go into explaining the role of the Macmillan nurse and our role and how we have taken over some of theirs. They don't have realistic expectations of us, they really expect the Macmillan nurses to come in, in their uniforms and sit all night with a relative. (DN)

The transition from 24-h nursing care in hospital to restricted periods of home care is a time of great uncertainty for many patients and their carers. Many have not fully thought through what home care will entail.

> I don't think they realise how hard it is when they come home from hospital. (DN)

District nurses identified the loss of the 'safety net' of hospital care as a factor in carer breakdown. Panic sets in among those who struggle to adjust and while district nurses attempt to respond as quickly as possible, they stressed that they 'are not emergency response'.

The duration of illness

The duration of an illness can impact on carers' ability to cope. The longer an illness continues, the more likely it is that carers will experience burnout. Those living alone or with few carers are perhaps less likely to remain at home as their condition deteriorates.

> I think it is very difficult where people live alone or sometimes where you have maybe got a very small number of carers. Where you have got big families where there's much more resources in terms of care input from the family, people are more likely to remain at home I find. (CNS)

However, having a large family or extensive group of carers does not guarantee that a patient will be enabled to remain at home. Both groups of nurses were aware of situations where carer breakdown occurred despite large families sharing the care.

> I think sometimes when there is a large family there is an expectation that there's lots of hands on deck . . . that they can cope because there is more of them and that isn't always necessarily the case. I've seen that with larger families . . . you can get quite pronounced family conflict and it takes a lot of skill to facilitate needs. (CNS)

The initial commitment to care can be severely tested if the situation persists longer than originally anticipated; many carers fall by the wayside.

> Especially when somebody lasts that little bit longer as well, isn't it, than is expected. They tend to have the full extended family there straight away and then over the next couple of weeks they just dwindle out really. They pull out all the stops if they think it is going to be a week or 2 weeks, but then run out. That's what happens when it goes on longer than they thought. (DN)

Informal carers do manage to continue to meet the patient's need for an extended period of time, but many often reach a point where they can no longer cope. This

frequently occurs suddenly in the very late stages of an illness.

> Particularly towards the final weeks of life I would say, people often manage to a certain degree at home and particularly with carers with social services and continuing care, but when it reaches the final . . . weeks and days of life when people are very dependent, that is when often it is more difficult to keep people at home when they actually need 24 h care. (CNS)

Ability to care

There is a sense that the general population in today's society has seen a loss of the ability to care for those who are ill.

> I don't think people these days are used to caring for sick people, they rely very heavily on health service and we can't be available very, very quickly, so people get very frightened and haven't got the skills that previous generations would have had. (DN)

There is also a feeling that many patients and carers have an unrealistic perception of the level and type of care that is provided in institutional settings, which they compare unfavourably with home care.

> I think they think home death is second best to hospice death and they are going to go into this place and they are going to get expert care and they think I couldn't possibly provide that at home. So they're feeling they are given less than they want. (CNS)

On occasion, tension develops when a carer feels unable to comply with the patient's request to be enabled to die at home, despite the availability of support from the healthcare services.

> I had a situation once where the man wanted to die at home and was desperate to die at home and all the way through his wife appeared to support him in that and then it was when he became bed bound, she suddenly broke down and actually said she would never be able to live in that house again after he died, if he died at home. (CNS)

While carers sometimes feel out of their depth, conflict can also arise when patients fear overburdening their family and perceive that their carers are less able than they really are. Patients may consider changing their preferred place of death out of a sense of protection for others, rather than considering their own needs.

> His wife is determined to look after him at home and wants him to die at home, but every time he sees her a little bit stressed or whatever, he breaks down and he says 'should I be going somewhere else, she can't do this'. (CNS)

DISCUSSION

This study aimed to explore the perceptions and experiences of community nurses as to why patients with cancer who had expressed a desire to die at home were being admitted to hospital. The results confirm previous research from both the UK and Australia (Thorpe 1993; Hinton 1994; Karlsen & Addington-Hall 1998; Payne *et al.* 1999; Tang & McCorkle 2003; Davies *et al.* 2006; Foreman *et al.* 2006; McKenzie *et al.* 2007; Zapart *et al.* 2007) that the informal carer is a vital factor in enabling home death to occur. Interestingly, the community nurses in the present study reported that strain on informal carers was exacerbated by unrealistic expectations of what community services are actually available. Thus, suggesting the need to explore what patients and carers understand is available to enable them to make an informed choice. Due to the wide variation in the role that informal carers have, it is essential to explore specific subgroups of informal carers to identify their needs and experiences rather than considering them a homogenous group (Navaie-Waliser *et al.* 2001).

The strain on the carers is also exacerbated by the duration of the illness was also apparent and is in keeping with the key finding of Gomes and Higginson's (2006) systematic review. They also identify that sharing the burden of caring among family members aids stress reduction; however, the findings of this study indicate that this does not always occur. The commitment of some extended family members to care appears to come under pressure if an illness persists longer than originally anticipated. Community nurses in this study acknowledge that those patients who live alone or who have few carers will be less able to remain at home at the end of life, a finding supported by Tiernan *et al.* (2002) who found that patients, even if receiving palliative homecare, but living alone, were less likely to die at home.

Furthermore, Munday *et al.* (2007) highlighted that agreement between patient and carer that a home death is preferred and is a strong indicator that a home death will be achieved. There is evidence within the current study that agreement may not always be possible. This is especially so where conflict exists between patient and carer; there may be fear of overburdening a carer or a carer may feel unable to comply with the patient's request to die at

home. The community nurses in this study felt that decisions about the place of death could be strongly influenced by the patient's perception of the carer's abilities.

When the results from the district nurses are compared with those of the clinical nurse specialists, it was found that the district nurses tended to focus on practical issues regarding care. For example, the reference to the loss of ability of the general population to care for people who are ill was identified by the district nurses. This is a point emphasised in the End of Life Care Strategy (Department of Health 2008) that also refers to the lack of experience the population has with dealing with death and the dying.

The clinical nurse specialists' discussion emphasised psychosocial factors such as family conflict, the emotional burden of caring and the stress on families of keeping a dying patient at home. This is not unexpected and is in keeping with the different roles that they both have. It also reflects the specialist training that palliative care clinical nurses specialists have, particularly in advanced communication skills (Jack *et al*. 2004).

One interesting point which emerged was the role confusion referred to by the district nurses concerning the general public's expectations and their misunderstanding of the district nurse role and the clinical nurse specialist role. It can be suggested that the emergence of palliative care training for generic staff and the roll out of the End of Life Care Strategy, and accompanying training programmes, have empowered the district nurses in delivering palliative care. This effect has previously been indicated in the hospital setting (Jack *et al*. 2003). This confusion over roles and of the availability of help and support for patients and carers in end of life care is highlighted as a priority in the End of Life Care Strategy (Department of Health 2008).

LIMITATIONS OF THE STUDY

The research was undertaken in two primary care settings (within the same region) and therefore the findings may not apply to other regions. Furthermore, the organisation, delivery and availability of palliative care services are not consistent across the UK and therefore further research in other locations is required. Thus, caution with the generalisability of the findings is needed. Moreover, the exploratory nature of the study meant that the sample was small and purposefully selected to only include nursing staff with an interest in palliative care; therefore, further research that includes less specialised nurses, medical staff, and importantly, past carers is undoubtedly required.

CONCLUSION

Despite the introduction of UK policy initiatives to promote choice in the place of death, it is clear that the role of the informal carer is fundamental to the choice of a home death being achieved. The strain on carers has been widely reported in the literature and appears to increase towards the end of life. The need for research to develop an assessment tool for carers or an adjunctive to the End of Life Care Programme tools that incorporates regular assessments of the carer strain and is supported by appropriate interventions is clearly required.

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